

PUBLIC HEALTH COMMITTEE HEARING

Wednesday, March 19, 2014

HB 5534 'An Act Concerning the Provisions of Services to Individual with Intellectual Disabilities

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My name is Dawn DeMatteo. I am currently on the Committee of 'Our Families Can't Wait' and fully support the proposed Bill HB5534 'An Act Concerning the Provision of Services to Individuals with Intellectual Disabilities'. A major issue arose when \$30 million was cut from DDS's budget and, as a result, those who were on the waiting list for residential services were faced with nothing to wait for ... dreams and hopes for their Children abolished. The goal of having a plan for these individuals was gone. The hope of being transitioned from their family home to a form of group home ~ depending upon the individual's need ~ was no longer in sight. Many of the families are still unaware of the situation with the residential waiting list and continue to wait for nothing.

I am one of those parents. I am a single Mother of a 21 year old, Anthony, who was diagnosed with Cerebral Palsy at birth. Anthony currently requires 24/7 supervision and is unable to perform any activities of daily living without full assistance. I have been the sole caregiver for him since birth and, of course, understand him the best.

Each day I am faced with making all the decisions relative to his life ... medical decisions, surgeries, schooling, day programs, etc. However, the most important decision for any parent with a child that has an intellectually and/or physical disability, is out of our control. I'm speaking of the appropriate living environment outside of his home. Due to the budget cuts, this major decision is deferred until the situation becomes an emergency ... most likely the death of a parent (myself). How can that be moral? How can we forget about these individuals?

Think about it ... This means that as a parent who knows my Child best, I will not be allowed to participate in Anthony's placement and will never know if he has found a good living environment for his particular needs. My dream for Anthony is to be in a group home with some of his peers. He loves visits to the Respite Center and would thrive in that environment.

Please take a moment and place yourself in our situation. I ask you for a few minutes per day ... maybe when you put your head on the pillow at night, when you are sipping your morning coffee, or any time in which you may have a few minutes to 'imagine' ...

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Picture your child, imagine him or her with a disability and that he or she requires your full help and attention to get through the day ... to function in this world or for that matter to survive. A child that is totally dependent upon you to continue to exist. Now, you are aging and faced with the thought of what may happen to this loved one when you are no longer around. Again, picture your Child and imagine how you would feel. I ask that you do this exercise a few minutes per day. No matter what race, nationality, or political side of the table you are on, this would be the most difficult situation for any parent, any human being.

This is what we, as parents, live and breathe every day and, for us, it's reality ... not just a few minutes of imagining. Let's go a step further and imagine how that individual, our Child, is going to feel when their life as they knew it is suddenly disrupted ~ they lost their sole supporter and are being placed into a strange environment. Think of a typical individual – young or old - and how it impacts them at the loss of a parent. These individuals (Our Children) will not understand what is happening. Their defender, advocate, parent, devotee is no longer there.

We have to do better for this population. This cannot be acceptable. I would like to believe that everyone - families, advocates, legislators, and officials agree. We need to work together as moral human beings to develop a variety of independent living arrangements that can fit the needs of these individuals. We need funds allocated back to DDS. The future of our Children depends upon it. We, as parents, are scared ... personally, I'm petrified.

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